STATEMENT BY

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BEFORE THE

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OVERSIGHT AND GOVERNMENT REFORM COMMITTEE

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Introduction

Congressman Wm. Lacy Clay and Members of the Subcommittee,

I would like to thank you for this opportunity to testify before the Subcommittee today on the issue of saving lives and I applaud the Subcommittee for bringing these important issues before the public. My goal is to share with the Subcommittee an organ procurement organization's perspective on donation.

My name is Sue Dunn. I am the President-Elect of the Association of Organ Procurement Organizations, otherwise known as AOPO. I am also the President and CEO of Donor Alliance, Inc., the federally designated organ procurement organization (OPO) that serves the donation service area of Colorado and most of Wyoming.

AOPO represents and serves all 58 federally designated OPOs through advocacy, support, and development of activities that will maximize the availability of organs and tissues and enhance the quality, effectiveness, and integrity of the donation process. AOPO is a professional organization that is dedicated to honoring donors and their families and meeting the needs of waiting recipients by providing education, information, research, and technical assistance to OPOs, and facilitating communication and understanding among OPOs, other healthcare organizations, and federal agencies to promote the goals of organ and tissue donation.

An OPO is a not for profit organization, by statute, that is federally designated by the Department of Health and Human Services. OPOs are responsible for identification and care of organ donors and their families, organ retrieval, organ preservation, transportation, and data follow up regarding deceased organ donors. OPO staff work with donor families, and educate medical staff and the general public about organ donation.

The Crisis

As of September 21, 2007, just this past Friday, nearly 100,000 Americans were waiting for a life saving organ transplant. Approximately 18 of these patients die every day while waiting for an organ that never comes. The growing divide between the number of people waiting for a transplant and the number of available organs has become a national health crisis. Most organs available for transplant come from deceased donors. In 2006 there were 22,201 transplanted organs from deceased donors and 6,729 from living donors. A deceased donor may donate up to seven solid organs in addition to bone, tissue, skin and eyes which can save or improve the lives of up to 50 people. Since each donor represents the potential of saving or improving 50 lives it means that maximizing the gift from every donor, every time is of extreme importance.

Extraordinary Results and Improvements

A National Experiment

Since the fall of 2003, an extraordinary development has occurred as the number of donors and the number of organs transplanted reached historic record increases as well as absolute levels. The Department of Health and Human Services joined with key national leaders and practitioners from the Nation's transplantation and hospital communities in 2003 to launch the Organ Donation Breakthrough Collaborative. The Collaborative was intended to dramatically increase access to transplantable organs. The purpose of the initiative was clear, measurable, ambitious, and achievable:

> *Committed to saving or enhancing thousands of lives a year by spreading known best practices to the Nation's largest hospitals to achieve organ donation rates of 75 percent or higher in these hospitals.*

This major commitment by all parties focused on the sharing of accountability by all sectors to increase donation. The focus is on the application of quality improvement, team-based approaches to this important endeavor and the increased involvement of the leadership of all organizations. The results have been impressive. Clearly, the United States is far from maximizing its supply of available organs from deceased donors. In 2002, only 6,617 (about 46 percent) of an estimated 14,000 potential donors donated organs. By 2006, however, the number exceeded 8,000.

Through a case study approach, it was determined that the successful programs all had

specific overarching principles and implemented effective practices that could be learned and replicated across the country to increase the number of organs available for transplantation. The Organ Donation Breakthrough Collaborative helped OPOs and their chosen large hospitals to close that gap rapidly. Multidisciplinary teams composed primarily of critical care nurses and OPO staff participated in intensive learning sessions and action periods. Participating teams achieved significantly higher organ donation rates.

AOPO's national study covering 1997-1999, published in the *New England Journal of Medicine* in 2003, documented that about 47 to 49 of every 100 medically suitable donors actually donated one or more organs. By 2006, that number had risen to around 63 to 64 percent. The national goal of 75 percent continues as a goal for all healthcare organizations.

Achieving the Collaborative's purpose of an average donation rate of 75 percent in the Nation's 200 largest hospitals saves or enhances thousands more lives each year. In 2002, the year before the Collaborative began; the number of organ donors was 6,190. In 2006 – the number of organ donors was 8,010. The first six months of 2007 show a continued upward trend for the number of organ donors on course to reach approximately 8,110 donors. (Beginning in 2004 there was a 10.8% rise in the number of organ donors as compared to the previous year, in 2005, there was an additional 5.9% increase.)

Organs Recovered and Transplanted for Each Donor is Also Critical

The number of organ donors is obviously important but so is the number of organs that are transplanted per donor. To increase those numbers, a second National experiment, the Organ Transplantation Breakthrough Collaborative was launched. Based on the same principles as the earlier experiment, this program involved members of transplant centers, donor hospitals, and the OPOs to form their multidisciplinary teams.

The teams focused on the effective practices of high performing transplant centers and began to share and implement those across the country. From 1999 through 2002, the average number of transplants per month was 1,616. In 2004 that number rose to 1,825 and continued its rise in 2005 and 2006 (1,940 and 2,039, respectively). Focusing on the 2006 numbers as compared to the 2002 numbers it is apparent that the number of lives saved increased substantially. Over the course of the year, greater than 5,000 additional lives were saved due to the increase in number of organs transplanted.

This gain, however, has occurred because of the huge increase in donors, unfortunately not matched to date by a corollary increase in the number of organs recovered and transplanted per donor. The challenge continues.

The 2006 Revised Uniform Anatomical Gift Act (UAGA)

With the organ donation crisis continuing to grow, AOPO undertook a review of the anatomical gift laws of fifty-four different jurisdictions, all of which had in place the

original 1968 UAGA or its 1987 revision. The findings were striking as the Association found that there were many issues with the existing state laws:

- *The anatomical gift laws were not uniform.*
- *The 1968 and 1987 versions of the UAGA failed to address the roles of OPOs.* Since the late 1980s, OPOs have administered the process of assessing and obtaining authorization for anatomical gifts. The OPOs, under federal law, are also responsible for assuring that anatomical gifts are properly managed, recovered, and allocated according to the national waiting list that is maintained by the federally mandated OPTN.
- *There was no standard definition of a donor registry, and no core requirements for their establishment or function.*
- *Healthcare agents or proxy holders under a durable healthcare power of attorney were not entitled to authorize post-mortem organ donation under the 1968 and 1987 UAGAs.*
- *The 1987 UAGA explicitly provides that no other person may revoke a document of gift and that the assent of no other person is required for a gift to be valid.* Although this was explicit in the 1987 language, some OPOs and hospitals had failed to follow the existing law so AOPO and others sought stronger and more clearly defined language to reinforce the intent of the document of gift.

After fully defining the issues with the existing laws, AOPO approached the National Conference of Commissioners on Uniform State Laws (NCCUSL) to see if it would be willing to work on another revision. As Howard J. Swibel, President of NCCUSL, stated, "Rarely do we as virtual legislators have the opportunity to literally save people's lives. This is such an opportunity, and we must seize it in earnest, since thousands are waiting for life-saving organ transplants."

The revised UAGA represents a significant, far reaching event. It is important to note that it relates only to deceased donors. Like prior versions, the centerpiece of the 2006

UAGA is the concept of "first-person" consent, under which no other person can alter the individual's decision to donate. The 2006 UAGA expressly bars a person from "making, amending, or revoking" an anatomical gift if that was the donor's wish.

The 2006 UAGA facilitates donation by expanding the list of individuals who may make an anatomical gift on a donor's behalf both during the donor's life and thereafter. The Act also expressly provides for the making of an anatomical gift on a donor registry, in addition to donor cards and driver's licenses. In time, donor registries may become the primary way people choose to make their anatomical gift known. The Act allows for the appropriate state agency to establish, or contract for the establishment of, a donor registry. It also sets forth three criteria for a well designed donor registry:

- The registry will allow a donor or other authorized person to make a gift on the registry by way of statement or symbol,
- The registry is accessible to all OPOs to determine whether an individual at or near death has made, amended, or revoked an anatomical gift,
- The registry must be accessible to donors, authorized persons acting on their behalf, and OPOs on a 24/7 basis.

If a decedent dies without having made an anatomical gift during life, the 2006 UAGA provides that a gift can be made on the decedent's behalf by his or her spouse, adult children, parents, adult siblings, grandparents, decedent's adult grandchildren, the individual who was acting as the decedent's agent under power of attorney at the time of death, and as well as any adult who exhibited special care and concern for the decedent. If none of these people are available, the gift may be made by the person having the

authority to dispose of the body of the decedent (i.e., coroner, medical examiner, hospital administrator, or government official).

Under the 2006 UAGA, any member of a class (such as all of the adult children of a decedent) may make a gift if he or she is unaware of any objections by other members of the class. If an objection is known, then the gift can only be made by a majority of the class members. The 2006 UAGA also prioritizes the anatomical gift's purpose (transplantation, therapy, research, or education).

In general, the 2006 UAGA incorporates a number of important new features that will increase organ, tissue and eye donation. The 2006 UAGA can play a major role in meeting the needs of those waiting for a life saving organ but only if all the state legislatures adopt the new language. As of September 21, 2007, the 2006 UAGA had been adopted by twenty states and legislation is pending in at least eight other states. Our Association and its members continue to work hard across the Nation in achieving broad Sate acceptance and incorporation of this important set of model legislative provisions.

DonorNet2007

Since inception of the OPTN in 1986, OPOs, transplant centers and histocompatibility labs have relied upon the telephone and the fax machine to make and review organ offers, collect and assess donor data and labs results, and ultimately accept or refuse a limited supply of transplantable organs. This voice and paper-based, work-intensive process

performed repetitively and usually under great pressure had allowed for some inaccuracies, miscommunications and human errors.

Patient safety, efficiency, accuracy and equity were foremost in the minds of those dedicated to the redesign of DonorNet and the implementation of an electronic organ placement system for the Nation. The new system allows transplant centers to quickly indicate to the OPO whether they *are* or *are not* interested in accepting the organ, so that the OPO coordinator's time can be dedicated to communicating with those centers that *are* interested.

DonorNet 2007 supports a central electronic environment that enables OPOs to make multiple, simultaneous organ offers according to policy, and provides qualifying transplant centers equal and immediate access to uniform donor data and lab results. The new system became available to the community in the fall of 2006 and became fully implemented in January 2007.

To ensure that OPOs and transplant centers' needs and concerns were addressed in the design and roll-out of the new system, the OPTN/UNOS Operations Committee established the Electronic Organ Placement Working Group, whose members include physicians and surgeons, organ and transplant coordinators and administrators from a variety of transplant centers, organ procurement organizations and histocompatibility labs, as well as representatives of the AST, ASTS, AOPO and NATCO.

The involvement of OPOs in support of the development and implementation of this major information technology has been critical. The bottom line effect has already been seen in reductions in the placement time for life saving organs.

Organ Donation and Recovery Improvement Act

Congress has the unique opportunity to assist in addressing financial disincentives to living organ donation, better coordinating organ donation in hospitals, and improving the science of donation. We ask you to support an initial appropriation of $2 million for Public Law 108-216 which is in the FY 2008 Labor, Health and Human Services, and Education appropriations bill. The law was signed in 2004 and was authorized for five years. The legislation is in the fourth year of its five year authorization. This is the last opportunity to obtain funding for implementation of the critical programs that can save lives.

As you may know, an increase in donor organs not only saves lives, but also saves the federal government millions of dollars in dialysis and other health care costs. In the case of living kidney donation, Medicare would avoid direct dialysis costs exceeding $55,000 per year for each patient transplanted.

The need for funding this year is more critical than ever. The Division of Transplantation has received cuts or level funding for the past four fiscal years. These cuts are in spite of the Office of Management and Budget's goal of doubling the number of transplanted organs by 2013. We share the opinion, along with many in Congress and the Administration, that enactment of the Organ Donation and Recovery Improvement Act of 2004 was a very positive step toward meeting the needs of people waiting for a

transplant. But, only with adequate appropriations will this bipartisan legislation allow the federal government, states, and other public and private entities to expand their current organ donation efforts and create new, effective organ donation programs.

Conclusion

Organ donation has seen an amazing increase over the past number of years. The spectacular force of positive action has been created by bringing together professionals from the OPOs, the donor hospitals, and the transplant centers. Other positive steps have been taken through legislative and policy efforts as well as improvements in the use of technology. The focus remains on the donor, the donor family and honoring their wishes. With the continued support of Congress, the Federal government and the stakeholders, we will be successful in saving more lives through donation and transplantation.

I would like to thank the Subcommittee for the opportunity to present the organ procurement organization perspective on the topic at hand and will look forward to answering any questions you have.